COVID INQUIRY MODULE 2B

WRITTEN SUBMISSIONS FOR PRELIMINARY HEARING 29 MARCH 2023

JOHN'S CAMPAIGN AND RELATIVES & RESIDENTS ASSOCIATION

A. INTRODUCTION

1. These written submissions address the following topics on behalf of John's Campaign and the Relatives and Residents Association (together, "**the CPs**"):
   1.1. Timetable
   1.2. Scope, Issues and Evidence
   1.3. Listening Exercise
   1.4. Parliamentary Privilege

2. These written submissions will be supplemented by oral submissions on behalf of the CPs at the preliminary hearing on 29 March 2023, though it is not envisaged that each of the topics raised in this note will be addressed orally. The Inquiry is respectfully requested, therefore, to take account of these written submission alongside the oral submissions made at the hearing.

B. TIMETABLE

3. The CPs are concerned by the indication given in CTI's Note for the Second Preliminary Hearing that the anticipated date of commencement of the public hearings in Module 2B will be delayed from Autumn 2023 until March 2024. It is of course appreciated that the Inquiry has a huge task. But it is also important for us to draw attention to the adverse effects of delay. These include delay in recommendations being made in interim reports, which benefit those who remain subject to restrictions due to covid and what the CPs would describe as a "covid mindset", which timely identification of limitations in the policy-making process and communication strategies might do much to dissipate.

4. Delays in the early modules have a knock-on effect on the timing of later modules, as the impact of the Module 1 delay on the timing of Module 2B exemplifies. The CPs are particularly concerned about delay in Module 3 and in the care sector module. The CPs wrote to the Chair on 14 March 2023 to invite her to commence the care sector module as Module 4. The letter is attached, for convenience. The primary reason for expediting that

module is so that a preliminary report can make recommendations to relieve the serious suffering of those in care and their relatives and carers, who remain subject to onerous restrictions related to covid. This continues to be a matter of significant public concern that is regularly reported in the national media[1]. Taking account of the 1-2 year life expectancy of care home residents, there is an urgent need to make recommendations to alleviate their distress.

C. SCOPE, ISSUES AND EVIDENCE

(a) Scope and issues

5. The CPs wrote to the Inquiry on 15 February 2023 regarding the scope of Module 2B. The letter is attached, for convenience. The CPs invite the Inquiry to confirm that the issues identified in that letter will fall within the scope of this module. For the reasons briefly given in that letter, the CPs submit that each of the identified issues should be considered in the course of Module 2B. They welcome the indication in CTI's Note for the Second Preliminary Hearing that a list of issues will be circulated to CPs, and invite the Chair to incorporate the issues in their 15 February letter within the list of issues. It would also assist the preparatory steps if early confirmation can be given that the issues identified in that letter fall within scope.

(b) Evidence

Rule 9 requests

6. The CPs note the invitation at paragraph 13 of the CTI's Note for the Second Preliminary Hearing to identify organisations or individuals to whom further Rule 9 requests should be made. The CPs consider that there *are* such additional organisations and entities, and therefore respectfully disagree with CTI that the Inquiry has already cast its investigative net sufficiently widely.

[1] (For example, the Guardian, 20 March 2023 "**Relatives locked out of UK care homes due to Covid call for visitor guarantee**. Anger grows at care homes still restricting visits three years on from start of lockdowns, causing 'extreme distress'": https://www.theguardian.com/uk-news/2023/mar/20/relatives-locked-out-of-uk-care-homes-call-for-visitor-guarantee)

7. In particular, the CPs consider that information provided on current Rule 9 requests, in Annex A to the CTI Note, suggests that the focus has been on service providers, and that there has been insufficient engagement with service users. In addition, the CPs are concerned to ensure that evidence is obtained on policy-makers' consideration of the safeguarding of vulnerable people in closed institutions. In this regard, the CPs suggest that a Rule 9 request ought to be made to the Care Inspectorate Wales who may have valuable evidence of the impact of policy decisions in such settings and on vulnerable care-users. The CPs also suggest that a Rule 9 request is made of Mary Wimbury, the Chief Executive of Care Forum Wales. The CPs are reviewing, in part by reference to the recent disclosure, whether there are any other specific organisations or individuals to whom Rule 9 requests should be made to ensure sufficient evidence is obtained from the perspective of care users, and to take account of the experience of the 310,000 unpaid carers in Wales, and will inform the Inquiry of any further suggestions as soon as we can.

8. The CPs also invite the Inquiry to consider obtaining evidence on the following topics. It is unclear whether (a) all those who were responsible for these matters have been asked under Rule 9 to give evidence, and (b) appropriate questions have been asked about these matters, due to the absence of disclosure of the Rule 9 requests. The CPs invite the Inquiry to clarify this, and to ensure that further witness statements are sought, if necessary:

    8.1. To what extent was Public Health Wales advice followed in core decision-making? For example, INQ000056324 is a document dated 19 July 2021 containing advice from PHW to the Chief Medical Officer for Wales, which indicates that closure of care homes is no longer proportionate, and less restrictive measures should be adopted. We invite the Inquiry to obtain a statement from the CMO (and/or other appropriate witnesses) to examined whether this and other PHW advice was followed, and if not why not.

    8.2. How was 'indirect harm' to individuals (such as harm caused by covid-related restrictions) evaluated and balanced against 'direct harm', in core decision-making? Was there any centralised methodology or guidance produced for performing this balance? For example, were particular individuals or bodies given responsibility for this, and if so, how did they implement the balance in practice in particular contexts?

A context where the interests on either side of the balance were particularly sensitive[2] is the care sector: what was done centrally to assist those responsible for the care sector to make policy and other judgments of this nature?

8.3. To what extent was core decision-making evidence-based? Was it sufficient, and should recommendations be made about this? For example: (a) How was the impact of NPIs monitored, and how did this feed into core decisions? (b) Was there adequate consultation? (c) To what extent were central decisions to discharge individuals from hospital to care homes based on evidence and data, and could or should evidence and data have better informed the relevant decision-making?

8.4. To what extent did decision-making take account of individual autonomy, and the rights or abilities of individuals to make key decisions about their lives? Was it sufficient, and should recommendations be made about this?

8.5. To what extent was the care-sector part of core decision-making? For example, was there a person or body centrally responsible for it? Given the far-reaching importance of restrictions in that sector (see, for example, the footnote below), was sufficient attention given to that sector in core decision-making?

8.6. How were key concepts defined? Which bodies were consulted? For example, were 'end-of-life' and 'exceptional circumstances' centrally defined, and if so how did this happen[3]?

9. Documents, such as INQ000022617, Annual Report and Accounts 2019-20, dated 14 July 2020, in some respects, make broad brush assertions such as engaging with stakeholders

[2] On 28 February 2022 the ONS reported that, since the beginning of the pandemic, there had been 228,431 deaths of care home residents from causes other than covid, and 45,632 deaths involving covid: www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/deathsinvolvingcovid19inthecaresectorenglandandwales/deathsregisteredbetweenweekending20march2020andweekending21january2022. The vast majority of deaths were not covid related. Many care home residents were prevented from having any contact with their families or carers during the end of their lives, due to covid restrictions, which caused huge distress. The restrictions on those in care were of far-reaching importance and ought to have been central to core decision-making.

[3] JC are concerned that there was real inconsistency with definitions of key concepts, such as 'exceptional circumstances' and 'end-of-life', and this led to serious problems, including death if individuals were placed on an end-of-life care pathway without full consideration of the potential for recovery or were refused access to their essential carers and loved ones despite being at the end of life. This was in part because important bodies were not involved in defining those concepts.

and the wider public to help resolve issues and support. This is not of any assistance to the inquiry of itself: further detail is necessary in order to test the adequacy of those assertions (such as which stakeholders were engaged, how, and disclosure of notes of the engagement). Will the inquiry be making further Rule 9 requests in order to obtain sufficient detail of broad-brush assertions such as this? If so, to avoid duplication of effort, could those Rule 9 requests be disclosed to CPs?

10. The focus of the disclosure reviewed so far appears to be significantly directed to the economy and funding issues rather than the impact of core decisions on individuals. It is unclear whether this is because of how questions in the Rule 9 requests were framed. If this has not occurred before now, further Rule 9 requests should be sent to relevant witnesses, to ask about the impact of the pandemic and the response to it on individuals, and how that impact and the interests of those individuals were factored into core decision-making.

Expert evidence

11. The CPs note and welcome the Chair's determination to obtain expert evidence on structural racism. They would welcome the expansion of this approach to seek evidence relating to other forms of structural discrimination.

12. They also invite the Inquiry to obtain expert input on:

12.1. The issue in §9.3 above. The CPs suggest **Professor Carl Heneghan** may be an appropriate expert to be instructed to give an opinion about this: www.phc.ox.ac.uk/team/carl-heneghan.

12.2. The issue in §9.4 above. The CPs suggest **Dr Lucy Series** may be an appropriate expert to be instructed to give an opinion about this: www.bristol.ac.uk/people/person/Lucy-Series-1a813fba-ca2c-493e-a1fc-66bbf606c8ae/.

Rule 10 proposals

13. The CPs would be grateful for clarification in respect of Rule 10 proposals as addressed at paragraphs 46-53 of the CTI Note for the Second Preliminary Hearing. In particular:

13.1. Will the evidence proposals described at paragraphs 50-51 be sent to the witnesses (as well as the CPs) in advance of the hearing?

13.2. Will CPs have an opportunity to ask questions in respect of new issues which only come up in the course of, or just before, a witness's evidence? It is often the case that new issues only arise during oral evidence (either of the witness themselves, or closely related previous witnesses), and the procedure ought to be flexible enough to allow CPs to effectively participate in respect of such issues.

13.3. Will the Inquiry consider allocating particular topics to CPs, if CTI considers the CP is best placed to ask questions about that topic, for example because they have a particular expertise about that topic? This would have the benefit of ensuring that those with relevant expertise are involved in questioning and are, accordingly, able to respond (by way of responsive questioning) to the evidence that is evinced in the course of the hearings.

D. PARLIAMENTARY PRIVILEGE

14. Broadly speaking, the CPs agree with the Inquiry's stance on parliamentary privilege as described in CTI's Note for the Second Preliminary Hearing, and in particular the proposal to seek evidence which duplicates what was said in the parliamentary context. The CPs agree that it is not at this stage necessary for the Chair to make any ruling about the scope of the privilege.

15. However, we would like to draw attention to the fact that there are a number of exceptions to the rule against the use of parliamentary materials in legal proceedings, which are likely to be relevant to this Inquiry. To pick a few examples, those exceptions include where the material is used in this context to identify Government policy, the reasons for a challenged decision, or the reasons for conduct outside Parliament; as a matter of historical record; and where the matter is uncontentious. These exceptions are well-established in the case law: e.g. *R (Heathrow Hub Ltd) v Secretary of State for Transport* [2020] EWCA Civ 213 at §158; *Wilson v. First County Trust (No. 2)* [2004] 1 AC 816, at §60, 113, and 142; *Toussaint v Attorney General of Saint Vincent and the Grenadines* [2007] 1 WLR 2825 at §10-21; *R v Secretary of State for the Home Department, ex p. Brind* [1991] AC

696, per Lord Ackner at 758-9; *Buchanan v. Jennings* [2005] 1 AC 115, at §16; *Office of Government Commerce v Information Commissioner* [2010] QB 98 at §64.

16. The CPs will seek to make fuller submissions on the application or otherwise of parliamentary privilege if it arises as an issue in the discharge of this module.

E. LISTENING EXERCISE

17. The CPs reiterate their concern that the listening exercise be expanded in an inclusive way to cater for the participation of individuals who are non-verbal or who communicate in non-conventional ways. The CPs attended the recent webinar on the listening exercise and they remain unclear about how if at all the exercise intends to achieve this.

18. Further, there was very limited notice of the time of the webinar and a restricted invitation list which the CPs consider reduced participation. For the listening exercise to be meaningful as the Inquiry's key public-facing initiative, it requires broad participation which the CPs are not currently confident will be achieved.

19. In addition, for the listening exercise to have a proper impact on the Inquiry's work, it must be conducted in a manner and at a time that permits it to feed in effectively to the different strands of the Inquiry's investigation. The CPs would appreciate greater transparency about how this is to be achieved as well as further explanation to ensure that evidence and views are captured in relation to all modules given the limited information about later modules as there is a risk the evidence provided to the listening exercise will be skewed towards these modules already opened.

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22 MARCH 2023

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Our Ref: REK/CXO/00451582/2
Date: 15 February 2023

Dear Inquiry Team,

1. We write on behalf of John's Campaign and the Relatives and Residents Association ("JC") regarding the scope of Module 2B. It is not clear to JC whether the following issues fall within the matters which the Inquiry will investigate in this module. It is important that it is clear at this stage whether these issues do fall within scope, because that is likely to inform the gathering of evidence. JC invite the Inquiry to confirm whether these issues will be examined in this module (or alternatively in another module). JC also invite the Inquiry to amend the wording of the 'Provisional Outline of Scope' to clarify the issues that will be examined.

2. The numbers in brackets refer to the paragraphs in the 'Provisional Outline of Scope' for this module dated August 2022[1] and the proposed additions to that wording are identified below. A brief explanation of JC's concerns which give rise to the proposed amendment is set out in italics. We would be happy to expand on this if that would assist.

[1] https://covid19.public-inquiry.uk/wp-content/uploads/2023/01/Module-2B-Outline-of-Scope.docx.pdf

a. Add to (3): Were appropriate bodies and individuals consulted in respect of decision-making?

   JC are concerned that there was inadequate consultation with the people affected by covid restrictions, and/or the bodies who represented them and/or who were responsible for their safeguarding.

b. Add to (3): How was the impact of NPIs monitored? Was any guidance provided about how to monitor? Was there a decision that there should be monitoring of the impact?

   JC are concerned that there was inadequate/insufficient monitoring of NPIs.

c. Add to (3): How were key concepts defined? Which bodies were involved and was there agreement between them? Was there consultation on appropriate definitions and their potential impact?

   JC are concerned that there was real inconsistency with definitions of key concepts, such as 'exceptional circumstances' and 'end-of-life', and this led to serious problems, including death if individuals were placed on an end-of-life care pathway without full consideration of the potential for recovery or were refused access to their essential carers and loved ones despite being at the end of life. This was in part because important bodies were not involved in defining those concepts.

d. Add the underlined words/remove crossed-out word, in (3):

> "the identification of at risk and other vulnerable groups in Wales, ~~and~~ the assessment of the likely impact of the contemplated NPIs on such groups in light of existing inequalities, and decision-making about NPIs relating to those groups;"

At present (3) does not clearly extend to decisions made about vulnerable or minority groups, what those decisions were and whether they were appropriate and proportionate. JC assume it is intended to extend to this, but this is an important issue, so it ought to be entirely clear.

e. Add to (3 or 6): The relevant existing legal and regulatory framework, and how this informed decision-making.

JC are concerned that core decisions were made that were not compatible with the existing legal and regulatory framework, such as the Mental Capacity Act 2005 and laws on safeguarding of vulnerable people, including those unable to communicate or advocate for themselves. They are also concerned that legislation was enacted which was not compatible with Human Rights and equality legislation, including the rights not to be unlawfully deprived of liberty and to be treated with dignity and respect. JC are aware that work was done in Wales showing the value of family carers reducing the risk of delirium among people with dementia in hospital and generally promoting their well-being and best chance of recovery. JC are concerned to highlight the need to examine whether this was considered when policies were made.

f. Add the underlined words/remove crossed-out word, in (4):

"Access to and use in decision-making of medical ~~and~~, scientific and care expertise, data collection and modelling relating to the spread of the virus in Wales; the measuring and understanding of transmission, infection, mutation, re-infection and death rates, including excess deaths caused by Covid-related restrictions rather than Covid itself in Wales; and the relationship between and operation of relevant systems for the collection, modelling and dissemination of data."

As to the proposed changes in line 1: JC are concerned to ensure that the involvement of unpaid carers/family carers across different settings is considered.

As to the proposed changes in lines 4 and 5: JC wish to highlight the importance of considering and giving adequate weight to the impact of Covid related restrictions on death rates and wellbeing. JC are also concerned about how 'cause of death' was recorded and monitored and whether approaches taken to averting Covid-related deaths were proportionate when bearing in mind the potential impact of Covid restrictions and resulting excess deaths.

g. Add to (5): Was there clarity about the distinction between 'law' and 'guidance', and the effect of each? Were there inconsistencies or gaps between 'law' and 'guidance'?

JC are concerned there was a lack of clarity about several important measures, which led to real problems on the ground. For example, some guidance was presented as binding law, leading to decisions being taken on a substantial scale which would otherwise not have been taken.

h. Add to (5): Who were designated 'communicators'? Were communications sent to providers of care as well as recipients? How were the family carers of people in the community supported to receive and understand policies?

JC are concerned that communications may have been impacted by those distributing them and the manner chosen to do so. JC are also concerned that communication to those cared for in the community rather than in other care settings may have been limited.

i. Add to (5): The clarity of information and instructions as well as support and encouragement given to the public and private bodies who were responsible for implementing core decisions.

There were a number of respects in which the bodies and providers who were responsible for implementing Welsh government policy were given inadequate support, or were not encouraged or compelled, to implement policy.

j. Add the underlined words to (6):

"The public health and coronavirus legislation and regulations that were proposed and enacted, <u>as well as the applicable guidance</u>: their proportionality and enforcement across Wales."

JC are concerned that a significant amount of 'regulation' happened via guidance and that the proportionality of its impact ought to have been kept under review. Restrictions on human rights (whether enacted through legislation or implemented through guidance) should be reasonable and proportionate and their reasonableness and proportionality should have been properly monitored.

3. There are three other matters which JC assume fall within the issues to be investigated in this module, and JC do not suggest these need to be formally added to the provisional scope of Module 2b. However, if the Inquiry considers these will not be examined, JC would be grateful if that can be stated now. Those issues are:

    a. the adequacy of policy or decision-making;

    b. whether decisions were appropriate in light not only of whether they put individuals at risk of contracting Covid, but also whether they had any other adverse impact, including harm to mental and emotional well-being; and

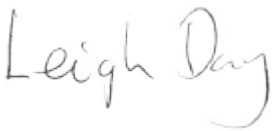
    c. decisions involving vulnerable people at home as well as those in institutional settings.

    JC are concerned that an inconsistent approach was taken as between different settings, which was not justified.

4. JC will produce written submissions in advance of the next hearing in respect of other matters, including rule 9 and experts. We have written about scope at this stage, in case the Inquiry can provide a response in advance of the next hearing, so this can inform JC's written submissions. For example, the Inquiry's response is likely to inform submissions about witnesses.

    We await your response.

    Yours faithfully,

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Our Ref: ELJ/TGY/00451582/3
Date: 14 March 2023

Dear Baroness Hallet

Module relating to the care home sector

I am writing on behalf of John's Campaign, the Relatives and Residents Association and the Patients Association, to ask you to ensure that the module concerning the care sector ('social care module') is the next module examined in this Inquiry (that is, module 4). This is appropriate for three reasons. Firstly, many people in, and connected to those in, care homes remain subject to onerous restrictions, so there is a pressing need for recommendations to be made which may benefit them. Secondly, the social care module is closely connected to Module 3. Thirdly, the average length of stay in a care home is between 1-2 years and the life expectancy of many of those affected in the social care sector is likely to be limited, so in order to capture the experience of people affected, the Inquiry must act quickly before it is too late for many individuals to provide any or meaningful input.

There have been a number of references to a later module that will relate to the care home sector.

In your opening to Module 3, you said:

Module 3, healthcare, is obviously at the heart of an inquiry into the Covid-19 pandemic. It is a huge topic and, as I've said before, my aim in conducting this Inquiry is to provide reports, interim reports, throughout the Inquiry and to make

timely recommendations where possible in the hope of reducing the suffering that we witnessed during the pandemic.

You went on to explain there will be a module dedicated to the care sector.

Those in care homes, and their relatives and carers, continue to suffer due to ongoing onerous restrictions on them. For example, many of the most vulnerable people in that context are prevented from having contact from those they love or their carers due to restrictions imposed as a result of perceived risk of infection. For many, there has been no 'freedom day' and the pandemic has fundamentally altered the way in which they can have contact with the outside world and their loved ones. Lessons should be learned as soon as possible in order to reduce that suffering. There is a pressing need for the Inquiry to examine this sector, and to produce interim reports with recommendations where possible.

The second reason why this would be appropriate is that Module 3 and the care sector are inextricably linked. One example you gave in your opening to Module 3 is the discharge of hospital patients into care homes. That is just one of many examples of the links between care provision in the health and care sector. Other examples include the self-isolation requirements imposed on many after appointments in healthcare settings, the resulting reluctance to seek medical assistance, which in turn impacted the provision of care, and the impact of restrictions which led to some individuals having to be moved out of care settings into healthcare settings (e.g. mental health settings). Because of the great overlap, it is likely to be to beneficial for all if the facts of M3 are freshly in mind when M4 begins; and by the same token, for you to have an understanding of the evidence in M4 when considering your conclusions in M3.

We also note that recent reports around the former Secretary of State for Health and Social Care Matt Hancock's whatsapp messages have further highlighted the overlap between issues in the health and care sector and decision-making in those contexts. We therefore also invite the Inquiry to ensure that requests for disclosure made in the context of both (interrelated) modules include requests for whatsapp messages that shed light on key issues and decisions made in this context.

The third reason it is appropriate for the social care module to be moved forward is that individuals affected tend to have a limited life expectancy making any further delay in trying to capture their experiences potentially very detrimental. By further delaying the collection of evidence from individuals who were affected in care

homes / social care more widely the Inquiry may lose valuable input from some of the groups most significantly affected by the pandemic.

Finally, the Terms of Reference make clear that the care sector is central to this Inquiry. It ought to be prioritised.

If you require any further information before making a determination, please do not hesitate to contact Emma Jones, by email (ejones@leighday.co.uk) or on 0771 4985037.

Yours sincerely
Emma Jones
Leigh Day